Excess Cervical Cancer Mortality Inevitable or Avoidable Transcript

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DR. KERNER: Before I give my brief overview summarizing what we've done today, I just wanted to point out that it is rather extraordinary to me that we have people from so many states, representing so many different populations, participating in this meeting and really helping us and each other to think through what are the issues that we need to address to meet Dr. Freeman's challenge of -- or to answer the question: "Why should any woman in America die of cervical cancer?" But I also want to point out that there has been an extraordinary level of cooperation and collaboration at the national level on this issue. So, for example, Nancy Lee and her team from the CDC have been incredibly important and helpful to us, in looking at data from the National Program of Cancer Registries. Irene Hall's group in epidemiology has been doing that, and the Behavioral Risk Factor Surveillance Survey data. We've had cooperation from the American College of Surgeons, Susan DesHarnais, who's been looking at treatment data. We have speakers coming from different universities. We have the American Cancer Society here. We have many, many national organizations represented. And as a person who was a cancer control investigator for 20 years and who used to watch the process from the field and wonder why people didn't work together more, this is an example of where we really have worked very closely together and it really is a change, I think, a sea change, that's been taking place, in many of our organizations, to try and build bridges and build collaborations. And so in a sense, one of your missions is to challenge us to do more. And tomorrow, you're going to have a chance to tell the national level folks, what it is we can do more of to help you deal with what's going on in your states. At the same time that we're trying to learn to play together better, we also want to figure out how you can learn to play together better in your states, and across your states, in your regions. So again, the extraordinary representation that Dr. Freeman alluded to here, is an opportunity for us to, like, really put our heads together and figure out, what more do we need to know and based on what we know now what kinds of policy recommendations and action steps can we take.

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So let me, with that little introduction, just quickly go over for you what we've accomplished today and what you're going to be hearing more about today. So, Dr. Freeman mentioned and alluded to the fact that we've have this extraordinary drop in cervical cancer mortality over the past 50 years. And this has been extraordinary, and if this was where the story stopped, we would all be going home and saying, "Great, we won the war."

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But the truth of the matter is that we still have populations reflected in this map of socioeconomic areas, clustered counties, that show for the period, 1950-1998, that despite the three-fold reduction in cervical cancer mortality, we still have pockets, hot-spots, counties, and communities and populations that are experiencing above average levels of cervical cancer mortality. And when this map was presented to the NCI Executive Committee about a year ago, around this time, Dr. Freeman, Dr. Harford, and Dr. Klausner, who has been the Director of the NCI, all looked at this and said, "this is something that we should try and address. This is something that we should try and focus on." And this is the reason why, in part, we're sitting here today.

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In terms of African-Americans, the last map was white, and by the way, let me just go back to that and make the point, that, when you look at the Texas-Mexico Border, we know that 95% of the quote, unquote, white population in that part of that country is Hispanic. So we have Latin Americans up there. But, as you'll see in a minute, and in this part, looking at

African-Americans, we see that there are patterns -- they are not same, exactly the same, as we saw for whites, but we see in the southeast part of the United States, up the mid-Atlantic, again, similar hot-spots, areas where there seems to be excess mortality. Now not represented on these maps are other very important populations, which when we started to do the surveillance evidence review, we got questions about -- "what about Native American populations: American Indians, and Alaska Natives?" We know that Northern Plains Indians and Alaska Natives have high cervical cancer mortality rates. What about Asian populations? The Vietnamese immigrants have some of the highest cervical cancer mortality rates in the nation. Well, the truth of the matter is -- once we looked at our surveillance data, we realized that we don't have systems that necessarily easily track that. That's it's hard to put a map up and show you where those communities are and where that high cervical cancer mortality is because of just the number of cases we are talking about. The number of deaths being relatively low and our surveillance systems, not necessarily able to track that very well. That will be a question that going to emerge as we move forward today about how we do a better job of monitoring who is at risk and helping those who are bearing an excess burden of cervical cancer.

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In terms of this map, what you see, is that there some -- when we first looked at this data, we were looking at '70 to '94 data, and so some raised the question, "Well, has it changed?" Maybe this is a phenomenon that's gone away. Well, when we put in '95 to '98 data, although there is some flipping of counties, because these are small numbers. The same general pattern for white populations appears whether you look at 1970 to 1994 or '90 to '94, or 1970 or 1998, or '95 to '98. There are still these hot spots. They're relatively stable given the small number of deaths we're talking about. And so, this raises the question, of "What is it about these populations or the services they may or may not have, that's contributing to this excess mortality?"

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You see the same pattern with African-Americans, where, although, when you add new data it doesn't dramatically change what we're seeing on those maps.

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So the three things that we explored in the surveillance evidence review and the literature review that you're going to hear about this morning,was: Well, maybe this is a function of risk factors and incidence variation, so we tried to look at that and see if we could sort that out. Was this a fact that they are just at a higher risk of developing invasive disease? Is it a variation in stage of disease of diagnosis? Do we have problems in screening and follow-up behaviors or access. And we'll be looking at stage of disease at diagnosis and behavioral data. And then finally, even if people are screened, if there is inadequate access or utilization of multi-modality cancer care for cervix cancer treatment, maybe that's part of the problem. So we've tried to sort this out and you will be the judges, of to what extent, what we've learned, what we know and what we don't know. And as Dr. Freeman said, "we need to apply what we know now. We can't wait to have all the answers." The questions are, "given what we know now, what can we do, and given what we don't know, what more do we need to find out?" What kinds of research activities have to take place to fill in the gaps of our knowledge.

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In terms of, we've developed a cancer control continuum at NCI, and I've plugged in the cervical cancer interventions there, although that light blue, I can't even read it, so I imagine you can't either. But in terms of prevention, obviously the issue of HPV and the question of developing a vaccine will come up. And when that's available, that would be a wonderful intervention, when and if that becomes available. Tobacco control is obviously an issue, because it's a co-factor in increasing risk. And barrier contraceptives, the use or

the failure to use them and number of partners, sexual exposure issues. These are all factors that contribute to the incidence of the disease. Dr. Freeman mentioned the Pap test -- we've had this test for over 50 years and it's clearly not -- it may be a factor that contributes to that. I hope that wasn't something I said. No. Okay. (Laughter.) DR. KERNER: In terms of diagnosis, there is the whole issue of clinical follow-up. When a woman has an abnormal Pap test, is there a failure in the system? What is the woman's reaction to the abnormality? Perhaps she's had an abnormality before, dealt with the system, has another one and didn't like the way she was treated in the system, so walks away, thinking that there's nothing that there's nothing she can do anyway and they are not going to be very nice to her. There are all sorts of factors that may contribute there. We talked about access to multi-modality treatment and quality. We are not going to talk too much about survivorship in this particular area. Because, although survivorship is a very important issue, it doesn't prevent mortality, unless, of course, you deal some of the psychosocial stuff that goes into that. But, largely we're going to focus on prevention, detection, diagnosis, and treatment issues. So the questions we have for you -- what are we missing? You're going to hear a lot of data. There is a lot of information that is going to be shared today. This morning it's all going to be about what we learned in the surveillance evidence reviews, and we're going to juxtapose that with the literature review, and we're going to have a chance to talk and each part of this continuum about questions you may have. What are we missing? What are things that we haven't looked at? But with what we know, what can we do? That is the other issue we need to address today and tomorrow based on what we've learned from this process and what we've known for many years.

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What are the action steps we can take? And when we talk about taking action, we need to think about it at many levels. At the national level, and Dr. Freeman alluded to the Policy Branch of the Center to Reduce Cancer Health Disparities, we may need to educate. Of course, we are not allowed to lobby, but some of you can. We need to educate Congress and other members of government about what the issues are and what might be done. At the regional level, there may be opportunities when you meet as regional groups to talk about leaders at the congressional level or state level or governors getting together, and perhaps focusing on this issue and trying to address whatever the issues are that we've identified from this review process that can be addressed at the state and regional level. And finally at the local level. You have state health departments, state legislators, governors, community leaders, community based organizations. There is a lot that can be done at the local level, and will have to be done at the local level. And what are the action plans we can develop there? So with that, the question that you need to struggle with for the next two days is, "What can we do?" and "how do we motivate action at all of these levels?" With the information you're going to get today and tomorrow, and that you're going to share back with us, how can we use that information to motivate action at all of these levels? And I thought Dr. Freeman's comment about, "well, why did we focus on cervix cancer?" This is a question that's come at me a number of times. Why didn't we pick a cancer that has a greater disease burden than cervix? Well, folks, let me just suggest to you, that those who refuse to learn from history are doomed to repeat it. If we cannot figure it out for cervix cancer, where we have an effective screening tool, we have effective treatment, how are we going to figure it out for breast cancer, how are we going to figure it out for colorectal cancer, where, frankly, the tools we have are less effective and we don't have a way of ensuring that every woman, in this case it's a disease of women, who's diagnosed early and treated effectively, can survive it. So this is what we need your help with. How do we motivate action? And with that, I am going to turn the program over to our next set of speakers. In your program you will see that we have divided the session up into, sort of, blocks. And so this next block is going to review the incidence and mortality data. Susan Devesa and Carol Kosary from the NCI and Irene Hall from the CDC are going to present some data. And then Robin Yabroff, from Georgetown, who we contracted with to do the literature review, is going to react to that data based on what

she saw in the literature review. Then we are going to ask all of the speakers to step up to this stage and sit-down and we will have a panel discussion with feedback and questions from you to the panelists about things that you've seen, issues that you think we missed, and perhaps implications of this data for action planning. So with that let me thank you all and turn the podium over to Susan Devesa.